



## **Collaborative Working Project Executive Summary**

### **Project Title**

Collaborative Working Project with HaemSTAR to Assess the Application of Shared Decision Making in the Management of Patients with Immune Thrombocytopenia.

### **Partner Organisations**

Sobi UK & ROI

HaemSTAR

### **Project Rationale, Objectives and Expected Outcomes**

Insights from the ITP Support Association (ITPSA) Patient Perception Study 2024 of 661 patients with immune thrombocytopenia (ITP) highlighted that;

- 29% of patients with ITP were unaware of their care plan, given the initiatives to move to “shared decision making” (SDM) between patient and clinician this number ideally could be improved<sup>1</sup>.

NICE Guideline NG197<sup>2</sup> covers how to make shared decision making a part of everyday care in healthcare settings. It promotes ways for healthcare professionals and people using the services to work together to make decisions about treatment and care. It includes recommendations on training, communicating risk, benefits and consequences, using decision aids, and how to embed shared decision making in organisational culture and practices.

This collaborative working project, in partnership with HaemSTAR, proposes to:

- 1- Conduct a quality improvement project via a haematology healthcare professional (HCP) survey to assess the current application of NICE Guideline NG197<sup>2</sup> when managing patients with ITP.
- 2- Share the ITPSA ‘A shared decision making toolkit for patients’<sup>3</sup> with all HaemSTAR members ensuring awareness of this SDM toolkit that can be used during consultations with patients with ITP.
- 3- Publish the outcomes of the survey to raise the awareness of the current application of NICE SDM Guidance when managing patients with ITP across the UK.
- 4- Sobi will support the ITPSA to re-do the ITP Patient Perception Survey in 2026 to assess the wider impact of this project on patients with ITP, details of which will be outside the scope of this project.
- 5- Sobi may also work with HaemSTAR where required, to support further SDM initiatives as a result of survey responses, details of which will be outside the scope of this project.

The project is expected to show variation in the application of NICE SDM amongst UK haematology healthcare professionals when managing patients with ITP.

**The intended benefits of this collaborative working project are listed below:****Benefits to patients:**

- To be confident that when undergoing a consultation with their HCP, their preferences, personal circumstances, goals, values and beliefs will be taken into account before a treatment decision is made

**Benefit to the NHS:**

- Raised awareness of NICE Guideline NG197
- Raised awareness of a shared decision making toolkit that HCPs can use with patients with ITP during consultations.

**Benefits to Sobi:**

- Developing a strong working relationship with HaemSTAR
- Improved reputation within the Haematology NHS stakeholder community.
- Improved knowledge of HCP barriers to applying SDM during patients with ITP consultations, allowing for the further development of supportive initiatives to continue to support NHS and patient outcomes (outside of the scope of this project).

**Resource Allocation**

Both Sobi and HaemSTAR are contributing resource to the successful completion of this collaborative working project.

- Sobi will provide funding and Sobi personnel time to help with the project development and management processes.
- HaemSTAR will provide HCP time to help with the project development and manage all stages of quality improvement project HCP survey, data collection and analysis, manuscript write up and publication processes.

Estimated project completion date October 2025.

**Contact Details**

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**References**

1. <https://itpsupport.org.uk/itpsa-patient-perception-study-2024-summary/>
2. <https://www.nice.org.uk/guidance/ng197>
3. <https://www.itpsupport.org.uk/download/ITP%20Shared%20Decision%20Making%20Toolkit%20FINAL%20Version.pdf>